**NACC UNIFORM DATA SET**

**COVID Impact Forms**

Version 2.0, July 2022

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Form F1 COVID-19 Technology Accessibility Survey
Form F2 COVID-19 Impact Survey: Participant, v2
Form F3 COVID-19 Impact Survey: Co-Participant, v2
Forms F2 and F3: COVID Impact Survey

Instructions for the Center

This updated COVID-19 survey is an optional form to be filled out by either the participant (if CDR® Dementia Staging Instrument score = 0 or 0.5) or co-participant/caregiver on behalf of the research participant (if CDR® > 0.5); alternatively, it may be administered by study personnel. Participants may decline to answer questions. If Centers want to obtain information on additional issues related to COVID-19, they may do so locally, but any additional material will not be collected for NACC.

This form serves as an update to the original COVID-19 impact Survey released in summer 2020, and reflects on several important updates since that time, including vaccinations, repeat infections, evolving understanding of the long-term impacts of COVID-19 particularly on cognitive function, and broader psychosocial stressors which occurred in the same timeline as the initial and subsequent waves of the pandemic. In addition, it is recognized that many of these aspects of the COVID-19 pandemic may have been experienced differently person to person as well as community to community. The survey is intended to capture a summative experience since the onset of the pandemic, may be used either during initial or follow-up visits, and is potentially adaptable to delivery between those times.

Attached to this participant form is a supplemental form for co-participants/caregivers of participants with a CDR® > 0.5. This survey is also optional for Centers. Again, if Centers want to obtain information on additional caregiver issues related to COVID-19, they may do so locally, but this additional material will not be collected for NACC.

These surveys may be administered by Centers in conjunction with, or unique and separate from, annual in-person or telephone UDS visits. The timing and option to participate in collection of this important data is entirely up to the individual Centers that are part of the NIA ADRC Program. Each Center should consider administering these surveys to as many participants as possible through either mail, telephone, video, and/or in-person contacts. Centers will need to provide information to participants about local vaccination availability for unvaccinated participants that request information.

We have tried to capture important scientific information regarding COVID-19 exposure, medical consequences, and impact on social situations; on cognitive, psychiatric, and behavioral issues; and on caregiver burden and related issues. This information may prove to be extremely useful in our understanding of the impact of such a pandemic on the aging population today and the future.

Form F2: COVID Impact Survey—Participant

ADRC name: ____________________ Participant ID: ________________ Form date: ___ ___ / ___ ___ / ___ ___ ___

Examiner’s Initials: ____________

For Clinical Staff

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>Is the participant’s CDR® &gt; 0.5?</td>
<td>0 No</td>
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<tr>
<td></td>
<td>1 Yes</td>
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<tr>
<td>Who will be filling in the F2 Participant form?</td>
<td>1 Participant</td>
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<tr>
<td></td>
<td>2 Co-participant</td>
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<td></td>
<td>3 Clinician</td>
</tr>
<tr>
<td>How are you administering the F2 form?</td>
<td>1 In-person electronic</td>
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<tr>
<td></td>
<td>2 In-person printed form</td>
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<td></td>
<td>3 Email</td>
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<td>4 Mail</td>
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continue to participant form...
**Form F2: COVID Impact Survey—Participant**

<table>
<thead>
<tr>
<th>ADRC name: __________________________</th>
<th>Participant ID: ________________</th>
<th>Form date: ___ / ___ / ___ ______</th>
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<tbody>
<tr>
<td>Examiner’s initials: ________________</td>
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</table>

The following COVID-19 survey is an **optional form** we would like you to fill out (or, alternatively, the survey may be administered to you by research study staff). We are asking these questions because COVID-19 has presented multiple challenges for us all, and we would like to learn about your experience. We also would like to learn how COVID-19 affects memory and health. As a research participant, you may decline to answer any of these questions, and it is alright to do so, but please answer as many of the questions as you feel comfortable with. Your research center may also have additional questions regarding COVID-19.

1. During the COVID-19 pandemic, have you tested positive for COVID-19 and/or were diagnosed with COVID-19 by a healthcare provider?

   - [ ] 0 No (CONTINUE)
   - [ ] 1 Yes, based on a positive test for acute infection (SKIP TO QUESTION 4)
   - [ ] 2 Yes, presumed COVID-19 diagnosis by healthcare provider but not tested (SKIP TO QUESTION 4)
   - [ ] 8 Decline to answer (CONTINUE)
   - [ ] 9 Unsure/unknown (CONTINUE)

2. During the COVID-19 pandemic, have you experienced new or worsening symptoms (see below) that led you to think you had COVID-19 (novel coronavirus) such as fever, cough, difficulty breathing, persistent pain or pressure in the chest, chills, repeated shaking with chills, muscle pain, headache, sore throat, new loss of taste or smell, new confusion or inability to arouse, or bluish lips or face?

   - [ ] 0 No
   - [ ] 1 Yes
   - [ ] 2 Other (SPECIFY):

3. Have you ever been tested for acute COVID-19 infection?

   - [ ] 1 No, not tested (wanted to but unable) (SKIP TO QUESTION 10)
   - [ ] 2 No, not tested (did not want to get tested) (SKIP TO QUESTION 10)
   - [ ] 3 Yes, I was tested once (SKIP TO QUESTION 10)
   - [ ] 4 Yes, I was tested more than once (SKIP TO QUESTION 10)
   - [ ] 8 Decline to answer (SKIP TO QUESTION 10)
   - [ ] 9 Unsure/Unknown (SKIP TO QUESTION 10)

4. If 100% is feeling perfectly normal (fully recovered from your COVID-19 symptoms), what percent of normal do you feel?

   - [ ] 0 No
   - [ ] 8 Decline to answer
   - [ ] 9 Unsure/unknown

   - [ ] 1 No, not tested (wanted to but unable) (SKIP TO QUESTION 10)
   - [ ] 2 No, not tested (did not want to get tested) (SKIP TO QUESTION 10)
   - [ ] 3 Yes, I was tested once (SKIP TO QUESTION 10)
   - [ ] 4 Yes, I was tested more than once (SKIP TO QUESTION 10)
   - [ ] 8 Decline to answer (SKIP TO QUESTION 10)
   - [ ] 9 Unsure/Unknown (SKIP TO QUESTION 10)

4a. If not 100%, why are you not feeling perfectly normal?

   ____________________________________________

   (IF QUESTION 4 = 100%, SKIP TO QUESTION 5)

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continued...
5. Over the past month, how often did symptoms from past or current COVID-19 infection(s) affect your daily life?

- □ 1 Never
- □ 2 Seldom (1-2 days per week)
- □ 3 Sometimes (3-4 days per week)
- □ 4 Often (5-6 days per week)
- □ 5 Every day
- □ 8 Decline to answer

6. How many times have you been diagnosed with COVID-19 (distinct episodes of infection)?

- □ 1 Once
- □ 2 Twice
- □ 3 Three or more times
- □ 9 Unsure/unknown

6a. When did your first COVID-19 infection begin (month/year)?

(88/8888 = Decline to answer, 99/9999 = Unknown)

___ ___ / ___ ___ ___

6b. What was the duration of symptoms from your first COVID-19 infection?

- □ 0 Never had symptoms
- □ 1 < 1 week
- □ 2 1-2 weeks
- □ 3 2-4 weeks
- □ 4 > 4 weeks
- □ 5 Not yet recovered (symptoms persist to the present)
- □ 8 Decline to answer

(IF QUESTION 6 = ONCE (ONLY DIAGNOSED ONCE), SKIP TO QUESTION 7)

6c. When did your most recent COVID-19 infection begin (month/year)?

(88/8888 = Decline to answer, 99/9999 = Unknown)

___ ___ / ___ ___ ___

6d. What was the duration of symptoms from your most recent COVID-19 infection?

- □ 0 Never had symptoms
- □ 1 < 1 week
- □ 2 1-2 weeks
- □ 3 2-4 weeks
- □ 4 > 4 weeks
- □ 5 Not yet recovered (symptoms persist to the present)
- □ 8 Decline to answer

7. During any of your COVID-19 infections, did you lose the ability to smell or taste, experience lower ability to determine smells or tastes, or experience episodes of unprovoked, unfamiliar, or strange smells or tastes?

- □ 0 No (SKIP TO QUESTION 8)
- □ 1 Yes (CONTINUE)
- □ 8 Decline to answer (SKIP TO QUESTION 8)
- □ 9 Unsure/unknown (SKIP TO QUESTION 8)
7a. When did you first experience changes in smell or taste (month/year)?
(88/8888 = Decline to answer, 99/9999 = Unknown)

7b. How long did it take to recover smell and taste fully?

- 1 < 1 week
- 2 1-2 weeks
- 3 2-4 weeks
- 4 > 4 weeks
- 5 Not yet recovered (symptoms persist to the present)
- 8 Decline to answer

8. During any of your COVID-19 infections, did you experience new problems with thinking, remembering, or concentration (e.g., brain fog)?

- 0 No (SKIP TO QUESTION 9)
- 1 Yes (CONTINUE)
- 8 Decline to answer (SKIP TO QUESTION 9)
- 9 Unsure/unknown (SKIP TO QUESTION 9)

8a. When did you first experience changes in thinking, remembering, or concentration (month/year)?
(88/8888 = Decline to answer, 99/9999 = Unknown)

8b. How long did it take to recover changes in thinking, remembering, or concentration?

- 1 < 1 week
- 2 1-2 weeks
- 3 2-4 weeks
- 4 > 4 weeks
- 5 Not yet recovered (symptoms persist to the present)
- 8 Decline to answer

9. Did you ever seek medical care for COVID-19?

- 0 No (SKIP TO QUESTION 10)
- 1 Yes (CONTINUE)
- 8 Decline to answer (SKIP TO QUESTION 10)
- 9 Unsure/unknown (SKIP TO QUESTION 10)

9a. Did you receive any type of outpatient treatment for your COVID-19 infection such as monoclonal antibody treatment, oral antiviral, subcutaneous injection of antiviral, or other treatment?

- 0 No (SKIP TO QUESTION 9b)
- 1 Yes (CONTINUE TO QUESTION 9a1)
- 8 Decline to answer (SKIP TO QUESTION 9b)
- 9 Unsure/unknown (SKIP TO QUESTION 9b)

9a1. When did you receive this outpatient treatment (month/year)?
(88/8888 = Decline to answer, 99/9999 = Unknown)
9b. What was the highest level of medical care you received for COVID-19?

- [ ] 1 Phone consultation or virtual care visit (SKIP TO QUESTION 10)
- [ ] 2 In-person physician or urgent care visit (SKIP TO QUESTION 10)
- [ ] 3 Emergency department (SKIP TO QUESTION 10)
- [ ] 4 Hospitalized but not the intensive care unit (ICU) (CONTINUE)
- [ ] 5 Hospitalized, including a stay in the ICU and/or ventilator support (breathing tube in your throat) (CONTINUE)
- [ ] 8 Decline to answer (SKIP TO QUESTION 10)
- [ ] 9 Unsure/unknown (SKIP TO QUESTION 10)

9c. How many times have you been admitted to the hospital for COVID-19?

- [ ] 1 Once (CONTINUE)
- [ ] 2 Twice (CONTINUE)
- [ ] 3 Three or more times (CONTINUE)
- [ ] 9 Unsure/unknown (SKIP TO QUESTION 10)

When were you admitted to the hospital for COVID-19? If you were hospitalized more than once, please report the 3 most recent hospitalizations.

9c1. Month/year of most recent hospitalization:
(88/8888 = Decline to answer, 99/9999 = Unknown)

___ ___ / ___ ___ ___ ___

9c2. How many days were you hospitalized?
(888 = Decline to answer, 999 = Unknown)

___ ___ ___

(IF ONLY HOSPITALIZED ONCE, SKIP TO QUESTION 10)

9c3. Month/year of next most recent hospitalization:
(88/8888 = Decline to answer, 99/9999 = Unknown)

___ ___ / ___ ___ ___ ___

9c4. How many days were you hospitalized?
(888 = Decline to answer, 999 = Unknown)

___ ___ ___

(IF ONLY HOSPITALIZED TWICE, SKIP TO QUESTION 10)

9c5. Month/year of next most recent hospitalization:
(88/8888 = Decline to answer, 99/9999 = Unknown)

___ ___ / ___ ___ ___ ___

9c6. How many days were you hospitalized?
(888 = Decline to answer, 999 = Unknown)

___ ___ ___

continued...
<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td>10. Have you received at least one vaccination against COVID-19?</td>
<td>0 No (CONTINUE) 1 Yes (SKIP TO QUESTION 10b) 8 Decline to answer (SKIP TO QUESTION 11) 9 Unsure/unknown (SKIP TO QUESTION 11)</td>
</tr>
<tr>
<td>10a. Why have you not received a COVID-19 vaccination?</td>
<td>1 Wanted to but unable (SKIP TO QUESTION 11) 2 Did not want to get vaccinated (SKIP TO QUESTION 11) 3 Allergy (SKIP TO QUESTION 11) 4 Medical contraindication (SPECIFY &amp; SKIP TO QUESTION 11): 5 Other (SPECIFY &amp; SKIP TO QUESTION 11): 8 Decline to answer (SKIP TO QUESTION 11) 9 Unsure/unknown (SKIP TO QUESTION 11)</td>
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<tr>
<td>10b. How many COVID-19 vaccine doses have you received?</td>
<td>1 One: Partial vaccination (one dose of two-dose series) 2 One: One-dose series, e.g., Janssen (Johnson &amp; Johnson) without booster 3 Two: Two-dose series without booster 4 Two: One-dose series with one booster 5 Three: Two-dose series with one booster 6 Three +: One-dose series with more than one booster 7 Four +: Two-dose series with more than one booster 8 Decline to answer (SKIP TO QUESTION 11) 9 Unsure/unknown (SKIP TO QUESTION 11)</td>
</tr>
<tr>
<td>10c1. When did you receive your first COVID-19 vaccination (month/year):</td>
<td>(88/8888 = Decline to answer, 99/9999 = Unknown)</td>
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<tr>
<td>10c2. Which COVID-19 vaccine did you first receive?</td>
<td>1 Pfizer 2 Moderna 3 Janssen (Johnson &amp; Johnson) 4 Other (SPECIFY): 8 Decline to answer 9 Unsure/unknown</td>
</tr>
<tr>
<td>10c3. Did you experience any symptoms within 5 days of your first COVID-19 vaccination?</td>
<td>0 No (SKIP TO QUESTION 10d1) 1 Yes (CONTINUE) 8 Decline to answer (SKIP TO QUESTION 10d1) 9 Unsure/unknown (SKIP TO QUESTION 10d1)</td>
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</table>
**10c4.** Which of the following symptoms did you experience after your first vaccine? (SELECT ALL THAT APPLY)

- [ ] 1 Sore arm
  
  **10c4a1.** Number of days sore arm lasted:
  
  (999 = Uncertain, 777 = Continued through now)

- [ ] 2 Flu-like feelings *(fever, chills, tiredness, or “malaise”)*
  
  **10c4b1.** Number of days flu-like feelings lasted:
  
  (999 = Uncertain, 777 = Continued through now)

- [ ] 3 New problems with memory, thinking, or concentration
  
  **10c4c1.** Number of days new problems with memory, thinking, or concentration lasted:
  
  (999 = Uncertain, 777 = Continued through now)

- [ ] 8 Decline to answer  
- [ ] 9 Unsure/unknown

**10d1.** When did you receive your second COVID-19 vaccination *(month/year)*?

(If Question 10b = 1 or 2 (one dose, no booster), skip to Question 11. If Question 10b = 4 or 6 (one dose with booster), skip to Question 10e1. If decline to answer, enter 88/8888. If date unknown, enter 99/9999.)

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**10d2.** Which COVID-19 vaccine did you receive?

- [ ] 1 Pfizer
- [ ] 2 Moderna
- [ ] 3 Other *(SPECIFY)*:

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**10d3.** Did you experience any symptoms within 5 days of your second COVID-19 vaccination?

- [ ] 0 No *(SKIP TO QUESTION 10e1)*
- [ ] 1 Yes *(CONTINUE)*

---

**10d4.** Which of the following symptoms did you experience after your second vaccine? (SELECT ALL THAT APPLY)

- [ ] 1 Sore arm
  
  **10d4a1.** Number of days sore arm lasted:
  
  (999 = Uncertain, 777 = Continued through now)

- [ ] 2 Flu-like feelings *(fever, chills, tiredness, or “malaise”)*
  
  **10d4b1.** Number of days flu-like feelings lasted:
  
  (999 = Uncertain, 777 = Continued through now)

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continued...
3. New problems with memory, thinking, or concentration

10d4c1. Number of days new problems with memory, thinking, or concentration lasted:
(999 = Uncertain, 777 = Continued through now)

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8. Decline to answer

9. Unsure/unknown

10e1. When did you receive your first COVID-19 booster vaccination (month/year)?
(If Question 10b = 3 (two-dose series without booster), skip to Question 11. If decline to answer, enter 88/8888.
If date unknown, enter 99/9999.)

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10e2. Which COVID-19 vaccine did you receive?

1. Pfizer

2. Moderna

3. Other (SPECIFY):

8. Decline to answer

9. Unsure/unknown

10e3. Did you experience any symptoms within 5 days of your first COVID-19 booster vaccination?

0. No (SKIP TO QUESTION 10f)

1. Yes (CONTINUE)

8. Decline to answer (SKIP TO QUESTION 10f)

9. Unsure/unknown (SKIP TO QUESTION 10f)

10e4. Which of the following symptoms did you experience after your first booster vaccination?
(SELECT ALL THAT APPLY)

1. Sore arm

10e4a1. Number of days sore arm lasted:
(999 = Uncertain, 777 = Continued through now)

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2. Flu-like feelings (fever, chills, tiredness, or "malaise")

10e4b1. Number of days flu-like feelings lasted:
(999 = Uncertain, 777 = Continued through now)

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3. New problems with memory, thinking, or concentration

10e4c1. Number of days new problems with memory, thinking, or concentration lasted:
(999 = Uncertain, 777 = Continued through now)

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8. Decline to answer

9. Unsure/unknown

continued...
10f. When was your most recent COVID-19 vaccination/booster (month/year)?
(If Question 10b = 4 or 5 (only one booster received), skip to Question 11. If decline to answer, enter 88/8888. If date unknown, enter 99/9999.)

___ ___ / ___ ___ ___ ___

11. Do you need help in setting up a COVID vaccination for yourself?

☐ 0 No  ☐ 8 Decline to answer
☐ 1 Yes (Center will provide information)  ☐ 9 Unsure/unknown

12. On a scale of 1-5, how worried are you that you will get COVID-19 (or, if previously infected, worried that you will get it again)?

☐ 1 Not at all worried  ☐ 4 Very worried
☐ 2 A little worried  ☐ 5 Extremely worried
☐ 3 Somewhat worried  ☐ 8 Decline to answer

13. On a scale of 1-5, how disruptive has the COVID-19 pandemic been to your everyday life?

☐ 1 Not at all disruptive  ☐ 4 Very disruptive
☐ 2 A little disruptive  ☐ 5 Extremely disruptive
☐ 3 Somewhat disruptive  ☐ 8 Decline to answer

14. On a scale of 1-6 (with 1 being “I can shake off stress” and 6 being “Stress eats away at me”) how would you rate your ability to handle stress?

☐ 1 “I can shake off stress”
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6 “Stress eats away at me”
☐ 8 Decline to answer

15. In the past year, on a scale of 1-6 with 1 being “no stress” and 6 being “extreme stress” how would you rate the amount of stress in your life (at home and at work)?

☐ 1 “No stress”
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6 “Extreme stress”
☐ 8 Decline to answer

16. On a scale of 1-5, how much has COVID-19 changed your willingness to participate in clinical research if it requires in-person visits to the research clinic?

☐ 1 Not at all  ☐ 4 Very much
☐ 2 A little  ☐ 5 Extremely
☐ 3 Somewhat  ☐ 8 Decline to answer
## Instructions for the Center

The following COVID-19 survey is an *optional form* we would like you to fill out *(alternatively, the survey may be administered to you by research study staff)*. We are asking these questions because COVID-19 has presented very new challenges for us all, and we would like to learn about your experience. We also would like to learn how COVID-19 may have affected your well-being and your ability to support the research participant as their co-participant/caregiver. You may decline to answer any of these questions, and it is alright to do so, but please answer as many of the questions as you feel comfortable with. Your research Center may also have additional questions regarding COVID-19.

### 1. On a scale of 1-5, how isolated or cut off from family and friends have you felt due to the COVID-19 pandemic?

- □ 1 = Not at all isolated
- □ 2 = A little isolated
- □ 3 = Somewhat isolated
- □ 4 = Very isolated
- □ 5 = Extremely isolated
- □ 8 = Decline to answer

### 2. On a scale of 1-5, how disruptive has the COVID-19 pandemic been to your everyday life?

- □ 1 = Not at all disruptive
- □ 2 = A little disruptive
- □ 3 = Somewhat disruptive
- □ 4 = Very disruptive
- □ 5 = Extremely disruptive
- □ 8 = Decline to answer

### 3. On a scale of 1-5, since the start of the COVID-19 pandemic, how often have you felt that you were unable to control the important things in your life?

- □ 1 = Never
- □ 2 = Almost never
- □ 3 = Sometimes
- □ 4 = Fairly often
- □ 5 = Very often
- □ 8 = Decline to answer

### 4. On a scale of 1-6 *(with 1 being “I can shake off stress” and 6 being “Stress eats away at me”)* how would you rate your ability to handle stress?

- □ 1 = “I can shake off stress”
- □ 2 = “I can handle stress”
- □ 3 = “I handle stress well”
- □ 4 = “I handle stress fairly well”
- □ 5 = “I handle stress sometimes”
- □ 6 = “Stress eats away at me”
- □ 8 = Decline to answer
5. In the past year, on a scale of 1-6 with 1 being “no stress” and 6 being “extreme stress” how would you rate the amount of stress in your life (at home and at work)?

☐ 1 “No stress”
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6 “Extreme stress”
☐ 8 Decline to answer

6. Regarding your feelings of connectedness with friends and family during the COVID-19 pandemic, did you feel or have you felt…

☐ 1 Less connected
☐ 2 About the same level of connection
☐ 3 More connected
☐ 8 Decline to answer

7. Has the COVID-19 pandemic affected your ability to provide care for the research participant?

☐ 1 It is easier to provide care
☐ 2 I am managing the same as always
☐ 3 It is somewhat more difficult to provide care
☐ 4 It is extremely difficult to provide care
☐ 8 Decline to answer

8. What kind of care assistance, if any, has become harder to access?

8a. Respite by family or friends
☐ 0 ☐ 1 ☐ 8

8b. Paid respite by care agencies
☐ 0 ☐ 1 ☐ 8

8c. Day activity programs
☐ 0 ☐ 1 ☐ 8

8d. Overnight or extended-stay respite care
☐ 0 ☐ 1 ☐ 8

8e. Ability to find skilled residential facility placement
☐ 0 ☐ 1 ☐ 8

8f. Medical care including physician appointments
☐ 0 ☐ 1 ☐ 8

8g. Other (SPECIFY):
☐ 0 ☐ 1 ☐ 8

continued...
9. On a scale of 1-5, how much has the COVID-19 pandemic changed your willingness to allow or encourage your care partner’s participation in clinical research if it requires in-person visits to the research clinic?

- [ ] 1 = Not at all
- [ ] 2 = A little
- [ ] 3 = Somewhat
- [ ] 4 = Very much
- [ ] 5 = Extremely
- [ ] 8 = Decline to answer

10. On a scale of 1-5, how much has the COVID-19 pandemic changed your own personal willingness to participate in clinical research, irrespective of whether in-person or telephone/remote visits are used?

- [ ] 1 = Not at all
- [ ] 2 = A little
- [ ] 3 = Somewhat
- [ ] 4 = Very much
- [ ] 5 = Extremely
- [ ] 8 = Decline to answer

11. Do you have specific care needs that are not addressed above?
   Please list any care needs (both yours and the research participant’s) that are not being met because of the COVID-19 pandemic:

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________